

**Autism Spectrum Disorders:
Understanding an Urgent Public Health Concern Conference
April 29, 2011**

Acknowledgements

Thank you Coleen for your ongoing efforts and support of New Jersey.

Thank you Amy for hosting us today.

A few words about Amy – I have known her for over a decade and she has consistently been a tireless advocate for children with special needs. She is a passionate leader who is always fighting for the population she serves. About a year ago, I had the opportunity to tour this facility with her and I was very impressed by the attention to every detail that went into building this facility in a way to support healing for the children and families who come here for care. I was also impressed by the fact that in each unit we visited, Amy knew the names of the patients, mothers and care team who we saw along our way.

New Jersey is very lucky to have Children's Specialized Hospital with the team of nurses, therapists, doctors and leaders that work together to make miracles happen every day. Thank you all for the great care you take in providing the highest quality services for children with special needs.

Parents, Advocates, Partners from the CDC and Coleen Boyle in particular, Acting National Director on Birth Defects and Developmental Disabilities –thank you all for being here today at this important conference.

Congratulations on the Center's 10th anniversary and the great work it has done to bring greater attention to the fields of birth defects, child development, and disability. Thank you for celebrating this important milestone here in New Jersey. The National Center on Birth Defects and Developmental Disabilities and the Departments of Health and Senior Services and Human Services have all made significant progress over the past decade to provide comprehensive services to children and adults with Autism Spectrum Disorders and other developmental disabilities.

I want to thank Coleen and the CDC for inviting me to be part of today's event to highlight our special partnership to advance the diagnosis and treatment of Autism Spectrum Disorders.

The CDC has been an incredible partner to the state. Through ongoing surveillance, research and outreach, your work helps us to better serve our residents.

I also want to thank our congressional representatives for joining us today and for their leadership.

Representative Smith has been a tireless, lifelong advocate for New Jersey families affected by Autism. He is the Co-Chair and Co-Founder of the Autism Coalition for

Autism Research and Education in Congress (CARE) and has been a strong proponent and champion on federal legislation for autism for many years.

Representative Pallone is a passionate advocate on all health care issues and has been a strong voice in bringing greater attention to autism. Also a member of CARE, he continues to lobby to dedicate more resources towards finding the causes of autism and providing the best possible services to children and adults with autism.

I also want to recognize Senator Menendez's Deputy Chief of Staff Kellie Drakeford LeDet who has joined us today. Senator Menendez, also an advocate for these important issues, was the author of the Helping Hands for Autism Act that includes a program to guide families seeking services and care, increase awareness among first responders and housing for adults with Autism Spectrum Disorders.

New Jersey is extremely fortunate to have such strong leaders for this cause at the federal level.

Autism Awareness Month

It is very fitting that we are gathered here today to share best practices and learn more about Autism Spectrum Disorders - because April is Autism Awareness Month. We use this month to raise awareness and promote a better understanding of autism and the need for compassion and acceptance.

In our state we have an incredible Autism advocate in First Lady Mary Pat Christie.

During the month of April, she has highlighted the innovative work being done by organizations throughout the state to serve people with Autism Spectrum Disorders. She has visited schools that provide education services for children with autism - and centers that help teach independent living skills. Her daughter Bridget's second-grade class participated in the 8th annual *Blow Bubbles 4 Autism Day* to promote autism awareness. Mrs. Christie will be joining us later today to talk about her commitment to bringing greater understanding to this developmental disability.

Promoting greater understanding of Autism is critical to helping those who are affected by it.

Many of our family members and friends face the challenge of having a loved one diagnosed with Autism. It has a profound effect on a family. Families experience the full spectrum of emotions. Some may feel overwhelmed; some may feel sad and others may feel relief just to have a diagnosis.

Thankfully in New Jersey we have many services available to assist families. Getting the appropriate services - in the right setting - at the right time - can have a dramatic impact on the quality of life.

I would like to highlight some of the important Department initiatives we are undertaking to assist and support impacted families.

EIS

One of the most successful initiatives in our state is the Early Intervention Services (EIS) Program. While all children grow and develop in unique ways, some children experience delays in their development. If a child experiences a developmental delay, this delay can compound over time and it may become more difficult to address.

The Early Intervention Program helps parents minimize the effects of delays or diagnosed conditions at the earliest stages. This program supports families with children from birth to age 3 who are in need of speech, physical therapy or other services necessary to achieve their full potential. Recognizing the importance of this program, Governor Christie increased funding for Early Intervention Services by \$17.6 million for a total of over \$100 million in the 2012 proposed budget. Services included in this program are early identification and referral, service coordination, evaluation and assessment and direct services. In 2010, more than 14,000 New Jersey children participated in the Early Intervention program. Approximately 800 of those children were suspected or known to have Autism Spectrum Disorder and subsequently received services.

Autism Registry

An important way to link our parents to services is through New Jersey's electronic Autism registry, which went live in 2009. The registry makes it easier for families to be connected to the appropriate diagnostic, treatment and support services in their communities. The Autism Registry requires medical professionals to register the children they are diagnosing with autism and birth defects such as Down's Syndrome, cleft palate and heart defects. Once registered, families are referred to a county case manager who works with the family and helps them to access available services. In addition to connecting families with services, the registry assists in improving current knowledge of Autism Spectrum Disorders and allows us to conduct epidemiologic surveys, analysis and provide services to affected children and families. As of today, more than 6,000 children have been registered and it is expected that approximately 1,200 children will be registered each year.

Autism Guidelines for Health Care Professionals

We know that early screening is critical for treatment to be the most effective. To assist providers in early identification, the Department has developed specialized guidelines for health professionals to evaluate infants and toddlers and improve early diagnosis. Under these guidelines, if a physician finds cause for concern, the child can be referred for evaluation at one of six state-funded centers of excellence.

Autism Training for First Responders

Part of serving those affected by Autism is ensuring their safety. In an emergency, every second counts, and the knowledge that a person has autism can greatly impact how to approach treatment. The signs of autism are not always easily recognizable. If first responders know those signs, they will be able to provide appropriate assistance.

In 2008, NJ passed a law that requires first responders to take a disabilities awareness training course. The Department then designed a training course called, "Do No Harm - Developmental Disabilities Awareness Training for NJ First Responders" which teaches how to recognize and respond to someone with autism or another developmental disability.

Governor's Council for Medical Research and Treatment of Autism

The Department also supports families through the work of the Governor's Council for Medical Research and Treatment of Autism. The Council, created in 1999, develops and funds basic and clinical research programs and clinical treatment initiatives. The Council has provided Clinical Enhancement grants designed to improve families' access to services, reduce wait times for receiving developmental evaluations, and increase the number of children that can be assessed by multidisciplinary evaluation teams. In 2008, the Council awarded over \$8 million in grants that enabled six clinical autism centers across New Jersey to enhance clinical staffing, improve early detection of ASD and increase evaluations they provide to children.

This is just a brief overview of what New Jersey does to provide services to the Autism community. This afternoon, staff from the Department and other state agencies will provide comprehensive presentations on these and other initiatives.

The services our state provides are all centered around one common goal—improving the lives of families affected by Autism.

New Jersey—from the state Legislature to Governor Chris Christie to federal representatives—has a strong commitment to improving early diagnosis, treatments and services in our state.

Together, we are making progress in the right direction and I look forward to building upon this work to achieve a better quality of life for children, adults and their families. - Thank you.